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ABSTRACT

This paper describes an ongoing study evaluating families that provide in-home care to elderly relatives wth dementia. Characteristics of the study, which include a focus on progressive senile dementia, use of a clinical approach, longitudinal design, descriptive nature, focus on the dyad of patient and primary caregiver, and use of videotaping for direct observation, are explained. The conceptual model used to organize data and the general research design of the study are described. The sequence of steps involved in evaluating families is given including: social history interview; physical exam; psychiatric evaluation; problem-oriented interviews; neuropsychological testing (patient); family history/social network interview (caregiver); take-home instruments; videotaped interactions; and wrap-up session. The methods used for measuring family dynamics and coping strategies, and suggestions for videotaping and quantifying family interactions are reviewed. Outcome measures devised specifically for this study are noted, and various other instruments used for data collection and evaluation are named. A series of 12 graphics illustrating the study components covered in the text is appended. (WAS)

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MEASURING FAMILY SYSTEM CHARACTERISTICS IN FAMILIES CARING FOR DEMENTIA PATIENTS

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MEASURING FAMILY SYSTEM CHARACTERISTICS IN

FAMILIES CARING FOR DEMENTIA PATIENTS

I very much appreciate the opportunity to participate in a symposium of this type, with its focus on measurement issues, since it allows me to share with you some of the work we are currently doing. I must warn you at the outset, however, that I will simply be reviewing the methods we are using to evaluate families, since we have not yet reached the point in data collection where I can report any actual findings from our project.

In the Gerontology Center at the Texas Research Institute of Mental Sciences in Houston, with the support of an NIMH research grant, we are conducting a study of families that provide care in their homes to elderly relatives with dementia. Our focal objective is to clarify ways that family system characteristics affect the process of caring for dementia patients. This first slide gives an overview of some of the primary features of our approach.

Present Slide 1 About Here

Our concern is specifically with the problems of progressive senile dementias, whether they be of the Alzheimer's type, or the cerebrovascular type. Many family studies with impaired elderly have failed to define clearly the etiology for their observed impairment. We, however, deal specifically with problems surrounding the dementing brain disorders.

Secondly, ours is a clinical study of the caregiving situation rather than a sociological or demographic one. We wish to understand better how to

deal clinically with the mental health issues that arise in caregiving families. We are studying families that come to a psychiatric setting for help, because this is the sub-population to which we wish to apply our findings. We realize that this is not a random sample of all such families in the community.

Thirdly, our research follows a longitudinal design. We are tracking our families over at least one year, and hopefully longer. Such longitudinal data will give us the ability to look prospectively at what consequences follow from various patterns of family interaction.

Fourthly, we are working in a descriptive and exploratory mode. Rather than formal hypothesis-testing of theories, we feel that the field very much needs careful and systematic descriptions of interpersonal processes in these families.

Although we aim to describe whole families in systemic terms, primarily we observe and describe a focal dyad, the patient and the primary caregiver. This relationship often reflects the broader organization of the family, but we also study a second caregiver from the family, whenever possible.

A distinctive point about our approach is that we directly observe interaction patterns within these families, using videotaping and subsequent coding of the interaction behaviors. We are not aware of any other published studies to date offering quanititative description of observed interaction in such families.

Finally, let me note a conceptual framework that underlies our methods. The existing literature tends to analyze the caregiving family in terms of two global constructs: "social support" and "burden". Both concepts seem too multi-dimensional to be measured in any unitary way, so we have tried to move to more specific measures of family functioning. For instance, we do not assume that what is "supportive" can be summed up in advance as any particular

form of behavior and thus be built into a descriptive measure of "support". According to our functional viewpoint, in certain families, interactions which are confrontive, argumentative, or detached may facilitate individual members' welfare over time better than those which would typically be considered "supportive" in some descriptive sense of being loving, tender, warm, etc. So, we attempt to look empirically at what outcomes actually flow from a given interaction pattern. We would tend to analyze this as "supportive" only if it is effective in maintaining a family member's well-being over time.

Present Slide 2 About Here

The next slide depicts a fairly simple model that we have used to organize our data. The top line shows the conceptual framework stated by Dean and Lin (1976) and others in the literature who have written about social supports as a buffer between stressful events and the ill effects they can produce. In our case, the stressor event is the onset of the dementia process in the older family member. In terms of illness or outcomes, we look separately at how this disease process affects the main family caregivers and the patient. You might note in the box below this column the major dimensions of outcomes that we are looking at. These include the physical, mental, and social adjustment of the various family members and the degree to which the patient maintains adequate cognitive functioning over time.

In this model, all of the variables of family dynamics and family interaction patterns become possible mediating variables. You will note that we group these mediating family variables into three rough categories:

a) background factors

b) resources and deprivations

c) current interaction patterns.

Present Slide 3 About Here

The next slide depicts our general research design. We are evaluating both a group of demented patients living in the community with their families and a comparison group of families with an older member in the household who is relatively well. We are attempting to stratify each of these groups so that in half the families, the primary caregiver is a child or other younger-generation relative of the patient, and in the other half, a same-generation relative (usually a spouse). After the initial evaluations, we are tracking all these families longitudinally by phone calls or other contacts, repeating some of our self-report measures after six months, and conducting follow-up assessments after one year. The numbers in the cells indicate only that we are evaluating more dementia families initially because we expect more sample attrition from this group. We hope to conclude one-year follow-ups with 10 families of each type.

Present Slide 4 About Here

This next slide shows the sequence of steps that families go through in our evaluations. Our dementia-patient familes are drawn from those coming to our geriatric outpatient clinic, where certain types of evaluation are done routinely. From this source we have information available on the patients' presenting problems, physical status, and psychiatric diagnosis.

The evaluation process in our study usually involves four additional steps. The first is a problem-oriented interview which we conduct separately with each participating family member to clarify his/her special concerns and viewpoints. Clinical interviews for symptoms of depression and anxiety are included. At a second session, the patient receives a battery of neuro-

psychological tests, while the caregiver is interviewed about the family's history, the current structure of the family and network of extended social relationships, and the experienced quality of the relationships involved. Following both the first and second sessions the caregiver is also given packets of self-report instruments to take home and fill out. These cover various facets of the caregiving situation, perceptions of the family's general functioning, and outcome measures of the caregiver's own current functioning and sense of well-being. During a third session, the family participates together in a series of interaction tasks that we videotape.

Present Slide 5 About Here

In this brief presentation, I cannot adequately describe all the multiple measures we are employing to assess various characteristics of the family system, either. This next slide simply shows some examples of components that typify how we break down the overall family context. Most of the measures we obtain in these areas come either from structured interviews, or from self-report inventories given to caregivers. In general we have borrowed heavily from the work of other researchers, but have also modified or added to their instruments in order to make them applicable to the kind of family situation we are looking at. For the items that are starred on this slide, we use measures that are clearly drawn from pre-existing instuments, and I need to acknowledge these debts. In the non-starred areas, the instruments are more of our own devising.

The social network interview should be starred, since it follows the procedures developed by Pattison et al. (1975). Our Stressful Events Checklist draws heavily on prior schedules published by Holmes and Rahe (1967), Paykel, Prusoff and Uhlenhuth (1971) and Lowenthal and Chiriboga (1973). To

measure "traditional family loyalties", such as the caregiver's degree of belief in family ties and obligations, we use primarily the 15-item Familism Scale of Heller (1980), and to get at caregiver's general perceptions of the family, the Family Environment Scale (Moos & Moos, 1976).

Present Slide 6 About Here

Our measure of "coping strategies" also borrows from work done by Moos and several other investigators who have developed coping scales (Billings and Moos, 1981; Folkman and Lazarus, 1980; Horowitz and Wilner, 1980). We have used items from these measures to inquire how the caregiver is coping in a general way with the responsibilities of caregiving. However, we have also devised many new items to tap the specific management styles the caregiver is employing to deal with behavioral problems that the patient shows. An example page from our Coping Strategies inventory is shown here to illustrate some of these items, and also the way in which we get estimates of how frequently various strategies are used and how helpful or effective the caregiver has found them to be.

Present Slide 7 About Here

This next slide shows a page from our Behavioral Problems Checklist. This is used to get an assessment of the patient's symptoms, deficits, and interpersonal behaviors, and how these are experienced by the caregiver. You can see that we ask about the frequency of various problems, how long they have lasted, and how upsetting these are for the caregiver. This instrument is basically a modification of a similar checklist devised by Steven Zarit at USC, but we have also incorporated some elements from the Geriatric Rating Scale (Plutchik et al, 1970) and from several Philadelphia Geriatric Center

scales assessing Physical Self-Maintenance and Instrumental Activities of Daily Living (Lawton, 1971).

Next, I would like to focus on the one part of our assessment methodology that doesn't rely on self-report data, so let me review our methods for videotaping and quantifying family interactions. In developing this portion of the study, we attempted to select from the direct observation literature those measures that most reliably differentiated distressed from non-distressed families, or that pinpointed "psychosomatic families," and we modified these to fit our experience with families coping with dementia.

As in most such studies, our measures can be related conceptually to two basic dimensions: an organizational one that deals with how the family handles issues of authority and control, decisions and conflict; and secondly, the quality of emotional response or attachment the family members display towards one another.

Present Slide 8 About Here

We designed five family tasks to elicit samples of family interaction, each taped for either ten or 15 minutes. The first two are discussion tasks and involve a three-person family group whenever possible. The family is first asked to plan pleasant activities that the members would enjoy doing together as a group, thus pulling for affiliative behavior. Next, we use a "revealed difference" technique to get at conflict-resolution. The family is asked to discuss a series of conflictual issues derived from the earlier individual interviews and to make decisions on how to handle each one. In the other three "helping tasks", the primary caregiver alone is asked to assist the patient in completing motor and verbal tasks, helping in any way short of actually doing the task for the patient. Here our concern is to get a sample of how situations of dependency and assistance are handled by the pair.

Present Slide 9 About Here

We quantify these family interactions by both coding and rating the videotapes. The "coding" process involves getting counts of relatively microscopic interaction behaviors. This process still lies ahead for us, and the categories shown in the slide are only examples from a more extensive coding scheme. But, for example, in the discussion tasks, the number of agreements and disagreements will be counted. Codes for the helping tasks will include such things as the giving of directions, criticisms, or positive reinforcement by the caregiver, or rejections of assistance by the patient. The videotapes will also be rated on more general dimensions, such as the structure of authority in the family, warmth versus hostility, task effectiveness, and repetition of unproductive helping strategies. Such ratings rely upon "clinical impressions" to get at dimensions that we currently have greater difficulty defining, or which are at a level too macro-scopic to allow frequency counts.

Following each discussion task we also have the family members rate their own interaction on several dimensions, including: how typical their interaction was, how important the topics were, and how emotionally affected they were by the discussion.

Present Slides 10 and 11 About Here

I will touch only briefly on the outcome measures we are using, because many of these are fairly well-known or standardized techniques. I'll just mention here a few measures we devised ourselves.

This slide (#10) shows how we are measuring physical and mental health in the dementia patients and the neuropsychological battery used to assess various aspects of their cognitive functioning over time.

This next slide (#11) shows our measures for caregiver well-being. The measures for mental health and social role functioning are standardized scales. We have devised our own questionnaire for physical health changes we wish to monitor in caregivers. The area termed "subjective strain" comes close to what others have called the "subjective sense of burden." In our overall Caregiving Questionnaire (CGQ), we have included a series of questions focused on how distressed the individual feels about the caregiving role, and how capable he/she feels about continuing in it. Another part of this questionnaire assesses the impact that the caregiving situation may be having on other family members whom we do not see directly in our study, including its perceived impact on the functioning of the family as an integrated unit.

Present Slide 12 About Here

Finally, this last slide just illustrates how we ultimately will be able to analyze our major domains of data, once the families have been tracked over a sufficient period of time. This particular slide depicts outcomes from the viewpoint of caregiver well-being. In cross-sectional analyses, we will be able to assess whether family system variables mediate the impact of dementia on caregiver well-being at successive points in time. We will also be able to assess how interaction patterns within the family change over time, in connection with the progression of the dementia.

At this point, however, our project is still at an early stage of data collection. I wish only to underline several major points exemplified in our general approach to caregiving families. Firstly, we have been concerned about doing exploratory clinical research with this population, and we feel that fine-grained constructs and measurements of family functioning, such as we have attempted, are a necessary tool for further developing this field of research, even for purposes of exploratory analyses. Obviously, we have felt

that appropriate instruments to serve our purposes were lacking. Thus we have opted to modify existing scales, or in some cases, simply to use several measures developed by prior researchers as inspirations for creating quite new or composite scales that we hope will more adequately tap the specific ecology of the caregiving situation. This reflects a larger concern at this initial stage of research with the validity rather than with the reliability of our measures.

We have also included a large number of measures that will give us a lot of data about a relatively small, but intensively studied, sample. We feel this is appropriate to our purposes of exploratory analysis and instrument refinement, but it does leave us with the burden of establishing the psychometric properties of our assessment techniques. Thus, our initial efforts in this project are necessarily directed largely at demonstrating reliabilty, validity and usability for the measures we have devised.

Secondly, an important facet of our work lies in combining, in the same study, both subjectively reported perceptions of family life and more observer-based data about actual interactions. Advances in our ability to describe families in broader, systemic terms will require that we find better ways of integrating both these phenomenological and objective sources of data.

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Slide 1

CHARACTERISTICS OF THE STUDY

- FOCUS ON DEMENTIA
- CLINICAL APPROACH
- LONGITUDINAL "TRACKING"
- DESCRIPTIVE, EXPLORATORY
- FOCAL DYAD
- DIRECT OBSERVATION OF INTERACTIONS
- ELABORATION OF "SUPPORT" AND "BURDEN"

Slide 2

Conceptual Scheme for Organization of Variables

INDEX EVENT	MODERATING VARIABLES	INDIVIDUAL OUTCOMES (Sequelae)

(Dean & Lin Categories)

STRESSOR ——→ (SOCIAL SUPPORT) ——→ ILLNESS

(Family Study)

DEMENTIA ——→ (FAMILY SYSTEM) ——→ CAREGIVER WELL-BEING

Specific Etiology	Background Factors -Personal -Interpersonal	Physical Health
Duration of Illness		Psychopathology
Symptom Pattern	Resources -Personal -Interpersonal	Role Function
Severity of Symptoms and Deficits		Cognitive Function (if elderly)
Functional Disabilities	Interactional Context -Personal (subjective) -Interpersonal	Subjective Strain

LONGITUDINAL RESEARCH PLAN

SAMPLING CATEGORIES		TIMES OF EVALUATION		
AGED'S DIAGNOSIS	DYADIC RELATIONSHIP	INITIAL ASSESSMENT (MONTH 1)	MAIL-OUT PROGRESS CHECK (MONTH 7)	FOLLOW-UP ASSESSMENT (MONTH 13)
DEMENTIA	SAME-GENERATION	15	12	10
"	CROSS-GENERATION	15	12	10
NORMAL	SAME-GENERATION	10	10	10
"	CROSS-GENERATION	10	10	10

Slide 3

Slide 4

EVALUATION PROCESS

- **CLINIC INTAKE**
  - Intake/Social History Interview
  - Physical Exam
  - Psychiatric Evaluation
- **FAMILY STUDY**
  - Problem-Oriented Interviews
  - Neuropsychological Testing (Patient)

    OR

    Family History/Social Network Interview (Caregiver)
  - Take-Home Instruments
  - Videotaped Interactions
  - "Wrap-up" Session

Slide 5

FAMILY SYSTEM (MEDIATING) VARIABLES

- **RESOURCES/DEPRIVATIONS**
  - Social Network/Family Structure
  - Sharing of Tasks
  - Use of Formal Supports
  - Stressful Events*
- **BACKGROUND FACTORS**
  - Family History
  - History of Dyadic Relationship
  - Prior Caregiving Experiences
  - Traditional Family Loyalties*
- **CURRENT INTERACTION**
  - Family Environment Scale*
  - Coping Strategies*
  - Problem Checklists*
  - Observed Communication Patterns

ACTIONS	HOW OFTEN HAVE YOU DONE THIS? 0 = never 1 = rarely 2 = sometimes 3 = fairly often 4 = all the time	HOW HELPFUL HAS IT BEEN? 0 = not at all 1 = a little bit 2 = a fair amount 3 = quite a lot 4 = extremely
55. I criticized or lectured myself on what I should have done differently	0 1 2 3 4	0 1 2 3 4
56. I blamed myself for having created the difficulties	0 1 2 3 4	0 1 2 3 4
57. I blamed my older relative for having created the difficulties	0 1 2 3 4	0 1 2 3 4
58. I try to arrange situations I hope will be stimulating to my older relative (mentally or emotionally)	0 1 2 3 4	0 1 2 3 4
59. I keep a close eye on what my older relative is doing so that I can head off any problems before they develop too far . . .	0 1 2 3 4	0 1 2 3 4
60. I try to engage my older relative in discussing his/her feelings and emotions . . .	0 1 2 3 4	0 1 2 3 4
61. I make a point of praising him/her when he/she does what I consider appropriate . .	0 1 2 3 4	0 1 2 3 4

Side 6

PROBLEMS	FREQUENCY How often does your relative show the problem? 0= never 1= not in past wk. 2= 1-2 times last wk. 3= 3-6 times last wk. 4= daily	DURATION When did the problem begin? 0= never 1= 1-6 mos. ago 2= 7-12 mos. ago 3= 13-24 mos. ago 4= 2+ years ago	REACTION How much does this problem bother or upset you? 0= not at all 1= a little 2= moderately 3= quite a lot 4= extremely
1. Having difficulty remembering how to do simple tasks	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
2. Losing or misplacing things	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
3. Not completing tasks	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
4. Not recognizing familiar people . . .	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
5. Forgetting what day it is	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
6. Forgetting his or her own name . . .	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
7. Getting lost inside the house (or apartment)	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
8. Withdrawing from others, failing to start conversations	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
9. Failing to do things he or she previously enjoyed (such as reading, hobbies, TV)	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4

Study 7

Slide 8

VIDEOTAPED INTERACTIONS

- **DISCUSSION TASKS**
  - **Plan Pleasant Activities**
  - **Discuss Conflictual Issues**
- **HELPING TASKS:**
  - **Assemble Block Designs**
  - **Construct T.A.T. Stories**
  - **Clarify Patient's Personal Concerns**

Slide 9

VIDEOTAPE MEASURES

METHOD OF ANALYSIS	DISCUSSION TASKS	HELPING TASKS
BEHAVIORAL CODING	Agreements Disagreements "Supportive" Statements Self-Statements Pos./Neg. Emotions	Directions Intrusions Criticisms Positive Reinforcements Pos./Neg. Emotions
OBSERVER RATINGS	Authority Warmth/Hostility Emotional Reactivity	Task Efficiency Repetition of Strategies Emotional Reactivity
SELF-RATINGS	Typicality Significance Emotional Intensity Reactivity to Setting	

Slide 10

PATIENT OUTCOMES

AREA	MEASURES
PHYSICAL HEALTH:	Physical Exam Physician Ratings
MENTAL HEALTH:	Hamilton Depression Scale Problem Behavior Checklist
ROLE FUNCTION:	Problem Behavior Checklist
COGNITIVE FUNCTION:	Mental Status Questionnaire Face-Hand Test Aphasia Screening Test Wechsler Memory Scale (Russell) Verbal Fluency Bender Gestalt Trailmaking Test Digit Cancellation

Slide 11

CAREGIVER OUTCOMES

AREA	MEASURES
PHYSICAL HEALTH:	Physical Heath Questionnaire
MENTAL HEALTH:	SCL-90 CES-D Scale Hamilton Depression Scale
ROLE FUNCTION:	Social Adjustment Scale
SUBJECTIVE STRAIN:	CGC "Feelings About Caregiving"
FAMILY UNIT:	CGC "Impact on Family"

Slide 12

Longitudinal Path Model of Cross-Lagged Panel Correlations for Causal Analysis